Room to Roar: Eliciting the Perspectives of Adolescent Oncology Patients

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Disclosures of potential conflicts of interest may be found at the end of this article.

Key Words. Adolescent • Pediatric oncology • Patient communication

For many months, my patient's lymphoma was nonresponsive, and he was verbally nonresponsive.

I met M when he was new to adolescence and I was a new pediatric oncology fellow. Keen to prioritize M's point of view in my initial history note taking, I determined to invest whatever additional post-call time this task required. I asked M when he first felt sick, and he stared silently until his mom said, "Four months ago," on his behalf. Gently turning my chair to position M's mom behind me, revealing my conversational priority in hearing from the patient himself, I then asked M what hurt. The voice, now coming from behind me, answered, "His belly, his back, his arms, his leg, and his chest." I smiled at M, inviting him to respond. He smiled back, silently. I decided that maybe M was overwhelmed with the newness of the diagnosis, and so I turned my ear to her narrative of his story.

M was on oxygen support for a number of days. I forgave him his silence in the setting of hypoxemia, although he could have spoken. In fact, M chattered with his younger brothers and his stepdad, but he became silent whenever someone from the health care team entered his intensive care room.

As a pediatric oncology trainee, I consider the voice of the patient pivotal to my work and core to my life's calling. Parental voice is approximate but accessory. Eager to meet the real M, I recruited the wisdom of Child Life forces and attempted to interact with M nonmedically. Just when I thought my inquiry about the "Chutes and Ladders" direction would be answered by M, his younger brothers would chime in. Just when I thought his giggle during a book reading would elaborate into a

comment, his lips would seal. Just when I thought he would address me or any member of the health care team before first discharge, he went home after a 21-day hospitalization without a word to the medical team.

I asked M the reason for his refusal to talk, which he responded to with silence. The psychologist thought the selective mutism could be partially credited to the steroids treating his underlying disease.

Or the silence, a form of control, was credited to M's sense of lost control over his diagnosis and his new surroundings. Therefore, I sought the perspective of M's baseline surroundings during his time as an outpatient. M's mom had asked me to call his teacher to clarify the duration of an anticipated school absence, at which time his teacher described M's childhood as "difficult." The pharmacy delivered antibiotics to M's urban apartment, and his mom called, sounding exasperated as she explained that neighbors had dug through the sealed postage box left on their front porch and strewn the antibiotics all over the street, apparently out of frustration that there were not other drugs in the pharmacy-labeled package. M's stepdad told me about M's new scooter, a surprise gift, commenting that he regretted M couldn't safely ride around his own block.

I asked M a nonmedical question during every appointment. He responded with a stare. Favorite animal? No answer. Favorite food? No answer. Favorite sport? No answer. Favorite color? No answer. Favorite doctor? Definitely, definitely no answer. Favorite season? No answer. Favorite book? No answer. I continued to address the appointment conversation

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to M's educational level and in his direction. M held my gaze with lots of blinking and an occasional eye roll. Sometimes M smiled at a joke. Not only was M stubbornly nonresponsive, his disease was nonresponsive. His lymphoma was not a clear diagnosis classification category based on pathology, just as M's age was not a clean, easy transition from childhood to adulthood. The international lymphoma groups were consulted, and the best minds in the oncology community spoke extensively about M's disease, debating best treatment plans and arguing most effective targeted interventions. Everyone was talking about M's case, and yet M still would not talk directly to his care team.

The attending physician and I told M and his mom the news of his lymphoma being, yet again, unresponsive to our therapies. We explained to M and his mom the need to change curative-directed protocols. In discussing family goals, I shared with M that I really wanted the best for him and that I felt we should keep fighting. I confessed that I felt baffled by this disease and yet determined. I added the realization that M having both a fellow physician and an attending physician was clearly adding stress by extending the duration of M's clinic time. M interrupted me by standing up, weak and yet forceful, to put his hand on my arm. With confident clarity, M declared, "Lion. Spaghetti-with-extra-tomatoes-how-my-grandma-makes-it. Football. Blue. No, green. No, blue-green, like aqua. Weaver. Summer. *Harry Potter*." He offered a loud, long, run-on-sentence dose of audible grace.

"Oh, I meant to say that other doctor's name."

Big smile.

"I think you said Weaver."

Bigger smile.

"Are we a team?"

Biggest smile.

The remarkable reality was that M did not require promptings between answers to my questions from months ago. I surely believed M had forgotten every question within an

hour of being asked. M is like his favorite animal. He roars when he's ready to roar. I actually already knew the lion was M's favorite animal because of the tattered pages of his *National Geographic* lion article clutched close during M's scheduled chemotherapy infusions. But hearing M give voice to claiming the lion was a declaration of M's presence, his participation, and his courageous new partnership.

The lessons learned through this patient interaction have the potential to inform purposeful inclusion of the adolescent patient's voice. These lessons include the following: respect the essential dyad while honoring the historic triad in history taking; offer open opportunities for adolescent patients to receive direct information, to ask questions, and to verbalize preferences; acknowledge that the responsibility for decision making may be sought by the adolescent as a form of independence or may be shared by the adolescent as a form of interdependence; and realize not just the positive potential for partnership but the actual priority for partnership.

M now speaks his own story at our clinic visits. He teases me that the wisdom of his voice was worth all these weeks of silence. We have started discussing the ways in which family dynamics, neighborhood contexts, and the health care system may unintentionally quiet teenage patients. As demonstrated in my experience with M, an important goal for this era of patient perspectives is to discover ways in which providers and parents can partner to elicit the adolescent's roar.

ACKNOWLEDGMENTS

The author wishes to thank Dr. Pamela Hinds (Children's National Medical Center, Washington, D.C.) for her encouragement to give voice to the lessons learned through this patient encounter.

DISCLOSURES

The author indicated no financial relationships.